

Survival instincts propel 'difficult patient' to insist on quality care

September 10 2008

Michelle Mayer had to become a "difficult patient" before she could get her physicians to accurately diagnose the disease that was destroying her health. And once the diagnosis was made, she had to continue to be what many physicians describe as "difficult" before she could get the best treatment for scleroderma, a chronic autoimmune disease in which hardening of the skin is a major element.

Mayer, a research assistant professor of health policy and management at the University of North Carolina at Chapel Hill School of Public Health, writes about her experiences as a patient in the September issue of *Health Affairs*, a publication aimed at enhancing communication between health policy researchers, legislators, decision-makers and professionals concerned with developing, implementing and analyzing health policy.

Mayer's essay from a patient's perspective is paired in the same issue by an essay from an Illinois physician, describing "difficult patients" from the physician's perspective. Their viewpoints are quite different, but, as the magazine explains, both Mayer and the physician decry policies that result in brief office visits that don't allow enough time for patients and doctors to get to know one another, discuss medical issues and reach appropriate decisions. They agree both patients and doctors need time to work together and listen to each other. Mayer said she is hoping to influence legislators and other policy makers to understand the consequences of certain policies and regulations.

In her essay, Mayer describes severe swelling and cold intolerance she developed in her hands 12 years ago while she was a public health student. She was diagnosed with Raynaud's phenomenon, a condition where small vessels of the hands and other parts of the body severely constrict in response to cold and stress, depriving surrounding tissues of oxygen.

"During the next six months I accumulated symptoms," she writes. "I'd been an avid cyclist, and suddenly I had difficulty getting out of bed each morning. When I returned to the rheumatology clinic for a follow-up appointment, the doctor attributed my symptoms to stress, irritably dismissing me with, 'You just have Raynaud's.' I knew that physicians often blamed stress for the 'inexplicable' ailments of young women; I refused to be dismissed so easily. I sought a second opinion from another rheumatologist at a different major academic medical center, and he reiterated the same diagnosis. Although I truly believed that I had scleroderma, I wanted to be wrong. So I acquiesced and, by doing so, caused further delay in my diagnosis."

Mayer goes on to describe years of inappropriate and ineffective treatment, struggles to get physicians to listen to her, and hopelessness.

"But my husband prodded me to fight," she writes, "and soon my survival instincts kicked into high gear."

She sought physicians who were supportive and helpful, traveling hundreds of miles for appointments. She and her husband longed to have children, so, after searching the medical literature, she determined she was not at high risk for developing complications for herself or the baby. Defying the recommendations of scleroderma experts, she became pregnant and, over 26 months, gave birth to two healthy babies without causing additional harm to her own condition.

"I've faced many decisions about my care during the past 12 years," she writes, "and my assertiveness has been greeted variably with contempt, resignation and, at times, support."

The doctor/patient relationship must be based on trust, she said. And that trust has to go both ways.

"I wasn't interested in being told what to do and I expected my doctors to respect my right to make truly informed choices that were consistent with the way in which I wanted to intervene in my disease and live my life," she writes. "But being a difficult patient is a tricky proposition. By advocating for myself, I risk incensing the person on whom I depend for care."

Efforts have been made recently to get patients more involved in their health care, Mayer said. She references health literacy initiatives, public reporting of quality indicators and consumer-directed health care. While these approaches aim to get patients more involved with their own treatment, they will fail if physicians are unwilling to make the transition to more patient-based care, she said.

"I don't regret being difficult," she writes, "but I do regret that so many people must settle for substandard care because they lack what it takes to advocate for their own needs."

She concludes: "We must rethink a system that disproportionately rewards medical testing and procedures rather than thorough and complete histories and physical exams. But ultimately, improvements in patient-provider communication will require a willingness to bridge the deep divide created by notions of professional dominance and a passive patient role. We will need to encourage patients and physicians to relate to each other as fellow human beings, each with much to bring to the examining table."

Source: University of North Carolina at Chapel Hill

Citation: Survival instincts propel 'difficult patient' to insist on quality care (2008, September 10)
retrieved 5 May 2024 from

<https://medicalxpress.com/news/2008-09-survival-instincts-propel-difficult-patient.html>

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